

# Helping



# Hands

Roles are redefined  
when you become the  
*caregiver* of a loved one.

By Amy Paturel, M.S., M.P.H.

*For as long as Jennifer Castro can remember*, she and her mom, Rebecca Utley, were best pals. Pregnant at just 17, Rebecca raised Jennifer on her own, and in a way, the two grew up together. In fact, for as long as Castro can remember, “It was just Mom and me.”

When Castro was 23, her mom began experiencing skin rashes, headaches, sun sensitivity, and fatigue, and was ultimately diagnosed with lupus. As the disease progressed, Utley filed for disability, stopped working, and spent most of her time in bed or on the couch.

“When I wasn’t working, I was taking care of her appointments, grocery shopping, cooking, cleaning, and picking up prescriptions. I wasn’t used to that kind of responsibility,” says Castro, now 33 and a pharmacy technician in Mabank, TX. “She didn’t want to be a burden, but there were days when she couldn’t walk from the bedroom to the bathroom by herself. It was really difficult for both of us.”

## *Roles Redefined*

Castro’s experience isn’t uncommon among caregivers. Many experience changing dynamics in their relationship when a loved one is handed a lupus diagnosis. “You have this additional role as caregiver, and that could change your relationship,” says Gail Hunt, president and CEO of the National Alliance for Caregiving.

Such changes can be uncomfortable for both the caregiver and the person with lupus, particularly when the transition involves taking on additional and sometimes nontraditional roles.

Keeley Moss is a 26-year-old cosmetologist in Franklin, LA, whose mom was diagnosed with lupus seven years ago. Before the diagnosis, Moss’ mother, Lisa, was in complete charge of the household and took care of the whole family. “Now, all she wants to do is stay in bed,” says Moss, who manages the household on her own. “Sometimes, she can’t even do simple things like run her own bath water.”

Even though she’s often exhausted, Moss does it all without complaint. “I realize it’s just as much of a struggle for my mom as it is for me,” she says. “My job is to make life as normal as possible for her.”

## Communicating in New Ways

It's not uncommon for parents to hold back information about how they're feeling, physically and emotionally, because they're worried about burdening their children, explains Joni Aldrich, author of *Understanding With Compassion: Help for Loved Ones and Caregivers of a Brain Illness Patient*. But that information is critical to providing the best care, whether the care recipient has lupus or another illness.

The key to managing these changing roles? Communication. The goal is to make sure the care receiver is honest with the caregiver about symptoms, pain, and illness, Aldrich says. Ask questions and be patient, but firm, as you await responses. "Carefully explain why their cooperation is needed and what each answer will tell you," says Aldrich. "If you have to repeat the reasons, use the exact same phrasing each time so it registers in their brain." Still no luck? Ask siblings and other family members to help, or turn to medical workers who may be able to relay the information more effectively.

According to Aldrich, caregivers and care receivers alike do best when there's some sense of normalcy. That means allowing the person with lupus to take on any roles and responsibilities he or she can manage. "Encourage care receivers to do as much as they can, perhaps by giving them simple tasks that will make them feel useful."

Even though Castro's mother couldn't do much physical work, Castro would encourage her mom to do a load of laundry from time to time or tidy up the kitchen. "I would also encourage her to go shopping with my aunt if she was feeling up to it, or I'd ask her to join me for a movie."

## Form a Support System

Caregivers shouldn't try to tackle their new role solo. "Early in the process, when you find out your loved one has lupus, make a list of local resources and



people who can help you when you're in a pinch," Aldrich says.

In many cases, the people on that list will be other family members: kids, brothers and sisters, aunts, uncles, even distant cousins.

When Rick Lyons' wife, Lori, was diagnosed with lupus in 1996, her symptoms were fairly mild at first. She struggled with skin problems, migraines, and heat sensitivity, but she was able to maintain a full-time job and care for their three sons. But in 2004, Lori was hospitalized for severe fatigue, and the couple knew roles around the house would change.

"She had to leave her job, and there came days when she couldn't work around the house, either. Sometimes she couldn't even make a sandwich," says Lyons. What's worse, Lori's illness hit when two of their boys were heading off to college. Without Lori's income, the couple couldn't afford their mortgage and other bills and eventually filed

for bankruptcy. "We lost our house and battled for two years to get Lori approved for Social Security disability income," Rick says.

During that time, their youngest son, Mike, who was 18 and living at home, stepped in. "He was a huge help," says Rick. "He went to the store for us, cooked us dinner, and did everything he could to make Lori laugh."

Mike, now 24, began collecting puppets and would entertain his mom with them, and, when she was up for it, he would take her shopping.

While family members can be a great resource, it's also important for caregivers to take advantage of other support services, Hunt says. "Investigate the options available for you at your workplace; for example, ask your supervisor if you can telecommute, or take a leave of absence, or use flex time for an extended vacation. Also, find out what federal assistance programs are available to you." If your parent, spouse, or a dependent child is affected, you may qualify for the Family Medical Leave Act.

Don't forget the treasure trove of information online. Not only can you identify support groups, respite care, and caregiver organizations, but online you can also connect with other caregivers, ask questions, and develop additional support networks. And don't be afraid to join a support group or get counseling if you need it. Counseling is available from many sources, including religious facilities, medical centers, and community centers. The Lupus Foundation of America (LFA) health educators can also offer resources and suggestions for counseling services; call them toll-free at (800) 558-0121.

"A lot of people don't take advantage of counseling," says Aldrich. "There's still a stigma attached to it, and some people don't want to discuss personal issues with strangers." But Aldrich stresses that asking for help to develop some life balance does not make you weak. In fact, she says, "working through



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such an emotional upheaval will make you a stronger person.”

Today, the Lyons family is back on its feet, enjoying what Rick calls a “good period,” one of the longest Lori has had in years. “You have to be able to laugh and have fun,” says Lyons. “We didn’t want to live in a bubble, so we never avoided any family get-togethers, even if we knew Lori would be in bed for the next three days. For us, it is all about

making the good times even better.”

Today, the two often sit outside watching the birds while they drink their coffee, taking pleasure in the little things they once took for granted.

### *Self-Care*

There is a danger, though, that caregivers can become so busy and overwhelmed that they push their own health aside. They neglect themselves,

focusing instead on the person they’re caring for. “Caregivers may know all about the latest clinical trials, but they don’t think about the toll caregiving is taking on their own health,” Hunt says. “They tend to neglect routine health issues.”

If you are a caregiver, consider this: Taking care of yourself is also good for the loved one you are helping. In many cases, the person with lupus is

## Are you one of the 5 million<sup>1</sup> individuals living with lupus?

If you are one of these individuals, we invite you to consider participating in the ILLUMINATE Research Study Program. The ILLUMINATE Program is evaluating a new investigational medication for systemic lupus erythematosus (SLE), the most common form of lupus.

If you or someone you know is **18 years of age or older** and has been **diagnosed with SLE**, then participation in this clinical research program could be an option for you. To determine if you may qualify to take part, our doctors and nurses will perform additional tests and health assessments.

Individuals who qualify will receive study medication and all study-related care at no charge. Reimbursement for study-related travel and time will be provided. Some standard lupus medications will also be permitted during study participation.

For further information, please feel free to contact us:

[www.illuminatestudy.com](http://www.illuminatestudy.com)



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Contacting us does not mean that you have to participate in this clinical research program and participation is completely voluntary

ready for the caregiver to get out of the house. "It's a good break for both parties," says Aldrich. "You can't be with someone 24/7, especially in a high-stress situation, without it beginning to wear on you."

Stephanie Agee's daughter, Kristin, 29, and son, James, 24, both have lupus and live with her. Currently, her daughter's symptoms are more severe. But Agee, 53, of North Las Vegas, NV, makes a point of participating in a bowling league twice a week. "You just have to find the time, and then plan for when you're away," says Agee, who makes sure someone is with her daughter on the days she bowls. "You have to allow yourself to enjoy whatever moments you do have, even if it's just five minutes."

Without focusing on their own care, caregivers can suffer burn-out, erupt in bursts of anger, or suffer nervous breakdowns. So leave the guilt behind. Eat properly, schedule your own doctor's appointments, and set aside time for a massage or meditation. Most of all, get some exercise.

Studies show that regular exercise is not only good for your body, but that it also improves your emotional health and well-being. Researchers from Northern Arizona University found that just 10 minutes of moderate exercise, such as a brisk stroll or a short bike ride, improves your mood and re-energizes you.

Plus, making time for yourself bears the alternative: getting sick. Experts agree it's not uncommon for caregivers to work themselves sick while taking care of their loved ones. Lyons, Castro, and Moss all struggled with their own health issues while still trying to act as caregivers. "When I was sick, my mom was trying to take care of me, and I felt

completely guilty," Castro says. "I was so concerned about her that I didn't really care what happened to me."

Moss had a similar experience when she was diagnosed with fibromyalgia two years ago. At times she feels too achy to move, much less keep up with her responsibilities as a caregiver and her own duties. That's why it's critical to have a list of people you can turn to.

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"When people want to help, let them help," Moss says. For example, Moss shares the responsibility of driving her mom to medical appointments with her dad and brother. "We try to rotate so I can get a bit of a break," she says.

### *Facing the Empty Nest*

Facing the loss of a loved one is always difficult, but if you're the primary caregiver, the emotional blow can be even greater. "When your 'shift' as a caregiver is over, loneliness, grief, and confusion may replace the feelings of being needed," says Aldrich. "Suddenly things are too quiet and you're not being pulled in three different directions. It can be very hard to fill the emptiness that's left

behind when you're no longer devoting your time and energy to daily caregiving."

Castro knows those feelings all too well. "My mom was always there, and we were always together," she says. "And for 10 years, I was her primary caregiver."

On June 1, 2010, Castro's mother passed away from complications of lupus. After her mother died, Castro found herself wanting to be around people—friends, family, anyone. So she packed up the car and took a road trip with her best friend. She spent a lot of time with her aunt and uncle, and she tried to adjust slowly to a life without her mom.

"You're not only losing a spouse or a sister or a mother, you're also losing a daily way of life and the time you spent together," says Aldrich. "That's an emotional double whammy."

There may be many tasks to distract you in those initial days and weeks following a loved one's death. But eventually former caregivers will need to create a new "normal." Experts agree it's important for caregivers to take it one step at a time to re-establish their footing. They should take some time for themselves

before jumping into a new hobby or a new career. Some former caregivers find a sense of purpose by supporting other caregivers, or volunteering their time to local community organizations. Such activities can provide a sense of accomplishment at a time when they're feeling lost and alone.

In April 2011, Castro and several of her family members participated in a fundraising walk for the LFA, North Texas Chapter. The group agreed to make it an annual tradition in honor of Castro's mom. "Everyone has a cause or charity they're partial to, and lupus is going to be mine," says Castro. "I feel like I'm still trying to adjust to life without Mom. I just have to take one day at a time."

While caregiving can be physically and emotionally demanding, there are rewards, too. As a caregiver, Moss has come to discover that she's giving herself the greatest gift. "I'm so close to my mom," she says. "I feel like I have to spend every moment with her while I still can."

## Caregiving Resources

Medicare-Approved Home Health Compare: [medicare.gov](http://medicare.gov)

Family Caregiver Alliance: [caregiver.org](http://caregiver.org)

National Family Caregivers Association: [nfcacares.org](http://nfcacares.org)

Caring From a Distance: [cfad.org](http://cfad.org)

National Association of Professional Geriatric Care Managers: [caremanager.org](http://caremanager.org)

Today's Caregiver: [caregiver.com](http://caregiver.com)



## How You Can Continue to Support the Lupus Foundation of America

- ▶ Make a secure tax deductible donation. Visit [www.lupus.org/donate](http://www.lupus.org/donate) or mail your check made payable to the Lupus Foundation of America (LFA), 2000 L Street, N.W., Suite 410, Washington, DC 20036.
- ▶ Register for *Walk for Lupus Now*®, the LFA's national Walk program raising funds to support programs of education, research, and advocacy. To find an LFA Walk in your community, visit [www.lupus.org/walk](http://www.lupus.org/walk).
- ▶ Get engaged with your local chapter activities—Participate/Support/Volunteer. To locate the chapter nearest you, visit [www.lupus.org/chapters](http://www.lupus.org/chapters).
- ▶ Create a *Page of Hope* and share your personal story, then invite family and friends to give in honor or in memory of someone in lieu of giving or getting gifts. Visit [www.lupus.org/pagesofhope](http://www.lupus.org/pagesofhope).
- ▶ Sign up as an e-advocate, and make your voice heard on Capitol Hill. You can also join us in Washington, DC for our annual Advocacy Day. To learn more, visit the LFA's Legislative Action Center at [www.lupus.org/advocacy](http://www.lupus.org/advocacy).
- ▶ Remember the LFA in your will and estate planning. Visit [www.lupus.org/plannedgiving](http://www.lupus.org/plannedgiving) for more information and language to use for bequests.
- ▶ Donate your gently used household goods to the LFA. Your donated items will be sold to for-profit wholesale buyers. Proceeds support the mission of the LFA. To schedule a pickup, visit [www.lfapickup.org](http://www.lfapickup.org).





## In Sickness and In Health

Men, especially those newly diagnosed, often feel alone and frustrated when trying to cope with a disease such as lupus. In each issue, we invite male readers to send questions to our psychology expert.

**Q.** Our 23-year-old son has been diagnosed with discoid and systemic lupus. While we are all afraid, we want to be as supportive as we can for him. He has been told the ups and downs of this disease and has been given medication. However, he is very adamant about not taking this medication because of the side effects, especially those affecting his glaucoma. While we as his parents are begging him to take this medication as prescribed by the doctor, he will not, and has chosen to research natural remedies (e.g., cleansing, vitamins). Please help us understand his decision.

**A.** Your son is an adult. He has lupus and glaucoma, and he has to cope with these challenges to his health, his hap-

piness, and his lifestyle. Continual and singular focus on prescribed medication could convey lack of understanding of his reluctance and lack of respect for his decisions. He needs to experience your genuine understanding about why he rejects, for now, these medications.

Be united with your son in his journey of coping with lupus. Encourage him to find out as much as he can about his lupus and the treatments offered by his doctor, and then trust that he will discover what medicines and treatments are most effective in helping him on that journey. Make sure he trusts that you know his feelings, and make sure he experiences your feelings of respect as well as concern. Let him guide you

in the ways you can be supportive. Let him feel, by your attentive listening, the depth of your understanding.

**Q.** In our little community, there is a man who has lupus. He has been trying to hide it from his six-year-old daughter, but now the child asks why her daddy is in bed so often, why he doesn't participate in games with children like other fathers, why he has those marks on his face, and so on. Because I am also a man with lupus, he has asked me how he should deal with his daughter's questions. Could you give me some guidance so I can, in turn, advise him?

**A.** The father who is trying to hide his lupus from his young daughter probably wants to shield her from difficult emotions such as fear, worry, and sadness. He might also be attempting to avoid the pain of delivering such disturbing news. But despite understandable intentions, he is shielding neither his child nor himself. His daughter senses something is wrong. Without carefully communicated information, she is left to imagine a reason for her father's changed behavior. What she is likely to imagine will inevitably be fearful and hurtful. The child, like the rest of us, when not understanding why someone changes toward us, will tend to think it is about herself: "Maybe Daddy doesn't love me as much anymore." "Maybe Daddy is mad at me because I was bad."

The daughter is going to have to cope with her father's lupus for years to come. She needs to hear information she can comprehend: that her father is sick and sometimes won't be able to play with her or take her places; that the illness has nothing to do with her or how she has behaved; that she is loved totally; and that Daddy is taking medicine and taking care of himself, just as he will continue to take care of her. The child will have to learn to cope when she is sad or when she is disappointed that her father is not available to her. She will also learn the joy, as well as the burden, of loving someone who is not always well.

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